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ABSTRACT

The number of Hispanic school-age children with hearing impairments in the United States is rising. Hispanic parents who discover that their baby has a hearing impairment lack basic information about deafness and experience guilt feelings about the cause of their child's hearing loss. They often do not know how to obtain information or medical care. Initiation of services in the school district often takes far too long, and parents are not familiar with the educational rights of their children. Parents do not understand how to care for, test, and encourage their child's use of hearing aids. The John Tracy Clinic in Los Angeles, California, is a private nonprofit agency that provides free educational, audiological, and psychological services to families that choose the oral communication option for their deaf children (ages birth through 6 years). The program is based on the principle that parents are their children's primary teachers of language. Hispanic parents undergo English-as-a-Second-Language training, parent classes, and support group sessions. The hearing-impaired children may attend the Clinic's nursery school. Clients who have successfully utilized the Clinic's services tend to be motivated, open to learning, energetic, flexible, and hard-working; clients come from varying socioeconomic and educational backgrounds. (JDD)

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Delivery of Services to Hispanic Families with Young Hearing-Impaired Children: One Model

PART I

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Miniseminar delivered at A.S.H.A.
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Recent demographics indicate a substantial surge in the Hispanic population of the United States. The rapidly rising numbers of Hispanic school age children are creating a revolution in the classrooms of California. This trend can be observed in the changes taking place at the John Tracy Clinic, located in central Los Angeles.

The Clinic offers an auditory-oral educational program to families with deaf children from birth through age 6. However, practically all the features shared in this presentation could be applied to programs which employ total communication or which serve clients with other disabilities. The Clinic, which also provides audiological and psychological services, is private and non-profit, and all services are free to the public. Participation by any family is entirely voluntary.

About 10 years ago the first Spanish-dominant family began using Clinic services and now well over half of the families enrolled are Spanish surnamed. This is not surprising, if we examine national demographic trends, especially focusing on urban areas where immigrants are clustered.

The percentage of Hispanics in all U.S. schools put together rose by 45 percent from 6.8 percent to 9.9 percent in the years 1978-1988. (See Graph No. 1). Likewise, the Hispanic hearing-impaired population increased at a rate that is 50 percent higher than that of the total population, from 8.6 percent to 12.8 percent during the same 10 year period.

The majority of U.S. Hispanics live in the five states of California, Texas, New York, Florida and Illinois. In these states, the urban centers where we find the largest Hispanic communities are Los Angeles, Dallas, New York, Chicago and Miami, with very significant numbers living in other large cities such as San Francisco, San Diego and Houston.

If we look closer at specific geographic areas, we find similar trends. In the State of California the incidence of school-age Hispanics rose from 23.6 percent in 1978 to 33.8 percent in 1988. (See Graph No. 2). The State of Texas saw a very similar proportion and increase, from 25.9 percent to 32.3 percent during the same 10 year period.

Looking specifically at the Los Angeles Unified School District, which emcompasses all of Los Angeles City and more than half of Los Angeles County, the figures are staggering. Eleven years ago 38 percent of all public school enrollees were Hispanic whereas last year Hispanic enrollment increased to 61 percent.

This latest figure explains why well over half of the families using our educational services are Hispanic. But why weren't 38 percent of our families Hispnic 10 years ago?

Like most new parents of a hearing-impaired child, recent immigrants from Latin America, as well as second or third generation Hispanics who discover that their baby has a hearing impairment, lack basic information about deafness. The usual guilt feelings they suffer are intensified by inaccurate beliefs about the cause of their

children's hearing loss. One mother cannot be dissuaded from believing that her child can't hear because she suffered a big scare during her pregnancy when she witnessed an auto accident. Another mother is convinced that a disgruntled relative paid a witch to cast a curse on her. One of the more poignant explanations was made by a mother with tears in her eyes who told us that she had to leave her daughter in Mexico as a baby with a grandmother so that she could come to the U.S. and get a job. She wasn't able to return for her until 2 years later and by then the gossip going around the village was that the child couldn't talk because she had been abandoned by her mother.

When Hispanic parents of a deaf child first begin to suspect a hearing loss, they often don't know where or how to look for information. Since many of them use public medical facilities they may not have established a trusting relationship with a specific pediatrician. Once a source of medical care has been found, they rarely know how to use it, as they have not been told of either their right or their need to play an active role in the health care of their children. Respect for, and deference to, authority is a basic Latin value. Medical care is often inadequate and comunication is poor due to the language barrier and a dearth of interpreters. Medical appointments must often be scheduled months in advance due to the overloaded system, so if a referral for an audiological evaluation is not managed during a routine examination, it may be another three months or more before the parent has contact with another medical professional. Since many hearing-impaired children suffer from multiple ear infections and the process of making audiological appointments may be confusing, time-consuming, and complicated by financial issues, a Hispanic baby may

easily be well into his third or even fourth year before a professional assessment is made. A procedure as simple as earwax removal in order to make earmolds may take weeks or months to get done. Consequently, the average age of diagnosis for the Clinic's Hispanic clients is 2 1/2 years, as contrasted to 1 1/2 years for the Anglo children.

Contact with and initiation of services in the school district often takes far too long. The parents don't know about the educatinal rights of their children. They are baffled by the IEP process and don't know what questions to ask. Even though an interpreter is usually present, the educational concepts and, objectives discussed are completely foreign to them and like many parents, they may feel that their presence is superfluous. When the educational plan is finally in place, it is usually far less than optimal, suffering from the "too little, too late" syndrome.

California Children's Services is a state agency that provides grants to cover all or part of the cost of hearing aids to low income families. The procedure involved in applying for financial aid and waiting for approval by C.C.S. usually takes 6 - 12 months, during which time most lower income children remain unaided. When the aids are finally received, most Hispanic parents do not know how to care for, test, and use the hearing aids. This is a problem that is shared by parents of any racial group but is greatly exacerbated by the language barrier. They don't understand the importance of training their child to wear the aids, let alone how to train the child to become aware of and responsive to sound. There is usually no one in the system who will convey this essential information to them in Spanish. Hispanics

tend to be less assertive with authority figures than Anglos due to cultural and linguistic differences. They're less likely to question statements made by professionals or ask for clarification.

All these problems that particularly affect the families of Hispanic hearing-impaired children only add to the day to day difficulties that are endured by recent Latino immigrants as well as second generation Hispanics.

It's hard to find stable employment, what with fluctuations in the economy, changing laws regarding the hiring of undocumented workers, the instability of day jobs which are often "under the table," and so forth.

Few recent immigrants find stable housing as they follow the jobs around the state or urban centers. Usually 2-3 families share an apartment. When one family moves, the other often can't afford the rent and must move out as well.

Due to the inadequate public transportation system many young Hispanic mothers don't go out much at all. They manage to conduct the household business within a radius of a few blocks where they visit the grocery store, laundromat, and school on foot. If the family is fortunate enough to own their own car, it may be old and unreliable. It is most likely that the father will use it to get to his work every day, so the mother will rarely have access to it. Even when she does, she may not know how to drive and may lack the self-confidence and minimal language skills necessary to pass a driving test. It is not very unusual for the Hispanic husband to be opposed to his wife learning how to drive. Auto insurance rates in California are unaffordably high; and driver's licenses get revoked for driving without insurance. The RTD bus system is so inadequate

that it is not unusual for Hispanic families to travel two hours each way three times a week to make it to Clinic appointments.

Few recently immigrated Mexican and Central American families are able to make the transition from their home country to the U.S. intact. Usually one parent will make the trip alone, and once he or she has found steady employment and a place to live, other family members will follow. This process may take one to ten years. For Latino families that are traditionally tight knit and loyal, such lengthy separations prove very painful and cause much social and emotional stress.

Hundreds of thousands of Central American families have been displaced by civil war in their countries, in particular, Salvadorans and Guatemalans, and to a lesser extent, Nicaraguans and Hondurans. Aproximately one tenth of all Salvadorans now live in the greater Los Angeles area. Many of these people have lost family members to the war.

When people are suffering from such basic issues and problems of survival, hearing loss may seem like a relatively low priority. What is foremost in these immigrants' minds is making it from one day to the next.

In this country, Hispanics are often faced with a relatively wide and bewildering array of choices and opportunities with regard to education, health care, eligility for social services, and welfare. I say "relatively" because they may come from a poor, rural part of Latin America where there is no choice or opportunity in the areas of health care and education, and no social or welfare systems.

In Latin America, which has its own version of baffling bureacracy, things are accomplished through personal contacts. If one wants to purchase an item which is difficult to obtain, or make a complex business transaction, or file a lawsuit, or get police protection from an abusive husband, or enroll a child in school, one finds someone in the system to help navigate one through. It might be someone one know or the friend of a friend.

When Hispanics enter an educational institution, medical establishment, welfare office, or social service agency in this country, they will often look for a contact inside the system with whom they will maintain a long-standing personal relationship. This person might be a receptionist, a teacher's aide, a counselor, or even a custodian. Without a close personal relationship, a Hispanic immigrant may feel lost, anonymous, or overlooked, and may drop out of services.

Delivery of Services to Hispanic Families

PART 2

Mary Beth Goring

The John Tracy Clinic is a private non-profit agency that provides free educational, audiological, and psychological services to families that choose the oral communication option for their deaf children (ages birth through 6 years). Our program is based on the principle that parents are their children's primary teachers of language. Another founding principal is that parents are likely to be much more effective in working with their children if they share the inevitable grief process with other parents who are dealing with similar issues. This helps them get past the depression, anxiety, and guilt to the hope and excitement of playing the pivotal role in their child's progress.

The Clinic's direct service staff is made up of educators, audiologists, psychologists, teacher aides and interpreters, many of whom are either fluently bilingual or have a working knowledge of the Spanish language. Several support staff also speak Spanish and are called on frequently to interpret when needed. Consequently, parents must never face a language barrier when receiving services, asking for information, or sharing concerns. Likewise, the staff is trained to be sensitive to cultural differences. We try to be aware of where the families have come from and the basic struggle to survive that many are dealing with.

True to our founding principle, full participation in our program requires a great deal of time and energy. There are parent classes, family classes, regular appointments, and special appointments to make.

Parents are expected to do "homework." They must restructure the time they spend with their children, must make changes in the methods and techniques of communication and behavior management, and family relationships inevitable change in the process.

In addition, our Hispanic parents undergo English as a Second Language training. They are expected to make a gradual shift to the use of English in their homes, particularly when communicating with their hearing-impaired child. We have found that there are no bilingual programs for the hearing-impaired to which the children can be sent once they have graduated from our services. While the Clinic's program is not bilingual per se, language differences are always accomodated in training the parents.

Why can't Hispanics families train their hearing-impaired children to become fluent in both English and Spanish from the beginning?

For any child, learning two languages simultaneously constitutes a heavy cognitive load in perception and differentiation of input stimuli, association of meaning, organization of storage strategies by acquisition of linguistic and phonologic rules, retrieval from the appropriate storage bank, and generation of output. If we add to this the disadvantage of the very limited audition of a profoundly deaf child, reliance on a completely different system of information gathering (i.e., visual cues) and the very complicated task of integrating acoustic and visual information which is perceived simultaneously by different organic receptors and processed through different cognitive systems, then the prognosis for acquiring a substantial and adequate language base in <u>either</u> oral language, let alone both, is not very hopeful.

In addition to all the time, energy, and social commitments required in order to successfully participate in our program, the family must have access to a reliable means of transportation and child care in order to attend their classes. Often, mothers will drop from full time outside work to part time, or leave their jobs altogether.

Many Hispanic families who are referred to the John Tracy Clinic for audiological evaluations are happy to find such comprehensive services and broad support systems available and they plunge in with great enthusiasm. Many others find that the commitment is too demanding and seek services elsewhere. Our clients tend to be motivated and highly focused, open to learning, energetic, flexible and hard-working. There doesn't seem to be a strong correlation between socieconomic status or educational level of the parents and success in our program. The common denominators appear to be motivation and commitment. The success stories represent a broad range of backgrounds. There is a family in our nursery school the mother of which is illiterate in Spanish, knew virtually no English at the time she first came to the Clinic, and has a daughter named Verônica who has been profoundly deaf from birth. This 5 1/2 year old now has an expressive vocabulary of hundreds of oral words and is spontaneously using sentences. On the other extreme is the father of a severe-to-profoundly deaf daughter named Cristina who was a college professor in Mexico. He immigrated to the U.S. after attending our summer session in 1987. At the time he knew very little English and struggled to understand the class content. His 5 1/2 year-old's expressive vocabulary is now comparable to that of Verônica.

Clients make the initial contact with the John Tracy Clinic when they are referred by physicians, hospitals, friends, audiologists, and T.V. ads for an audiological evaluation. If they speak Spanish only, a bilingual member of our clerical staff will take down the standard information we ask and secure an appointment with the audiologist.

When the clients arrive for their appointment they are greeted by the receptionist and make immediate contact with a Spanish-speaking staff member who assists the audiologist, who herself speaks limited Spanish, in interviewing the parents and testing the child. With the help of the interpreter, the audiologist discusses hearing aids, ear-molds, the audiogram and any other relevant information. When appropriate, she'll make a referral to the school district, medical specialist, the hospital where an ABR can be performed, California Children's Services, etc. When children arrive at John Tracy Clinic without aids, or with inadequate ones, the Clinic provides loaner aids until permanent ones can be secured through California Children's Services, a process that usually takes 6-12 months. In the cases where an initial diagnosis is being made or the family otherwise seems to show a need, the Spanish speaking counselor is called in for an informal counseling session.

Parents might sort through feelings at this time or discuss the impact of the child's hearing loss on family relationships or lifestyle, or express their fears and concerns. The process of sharing emotionally charged content is often not amenable to simultaneous interpretation; in fact, interpretation may inhibit its expression. The parent should not be interrupted while expressing her feelings lest the flow of her subjective experience come to and end.

If the family expresses interest in the Clinic's educational services, then they are invited to Tuesday evening parent classes and Friday Family School. These experiences are available to all parents of deaf children regardless of whether they use other Clinic services.

The Tuesday night classes take place every week from September to May at 7 - 9 p.m. During the first hour the parents attend a "communications" class. Educators on the staff teach such topics as communication options for the deaf, how to read an audiogram, vocal play, talking techniques, reading to your deaf child, pre-lingual development, evidence gaining, and many others.

The classes are divided into three levels according to how much time the parents have spent in the program. During the first year or two the Spanish-speaking families receive these content classes in Spanish. The third year they often move into a higher level English class as their English skills improve.

During the second hour the parents participate in a support group facilitated by the bilingual family counselor. These groups are also divided according to language and level. Because this is a process experience rather than a content class it is important that it take place in their own language without interpreters present. This is a chance for the Hispanic community to converse informally and exchange ideas. They share feelings, experiences, hopes, discouragement, relationships, problems, and resources. Bonding takes place here, friendships are formed, and relationships deepen. Parents no longer feel isolated with their worries. They share a common language,

traditions, cultural values, and concern for their hearing-impaired children and their families. Newer parents look to their more experienced peers for guidance, hope, and encourgament.

On the first Tuesday of every month the Clinic parents' association plans a special theme night. Usually a special speaker is brought in to discuss a topic of common interest. There might be an oral deaf adult panel, and ear nose and throat doctor, a cued speech expert, someone from the school district to discuss IEP's, or any number of possible speakers. On these occasions, headsets are worn by the Spanish-speaking parents while the interpreter speaks softly into a mike.

Friday Family School is held from 9 - 12 each Friday morning from September to May. At this time parents bring their newly diagnosed hearing-impaired children and any other children who are not attending school. Mothers are more likely than fathers to attend Friday Family School due to work scheduling conflicts.

The first hour is spent in the nursery school learning how to use play to enhance the child's communication skills. It's a time to interact naturally with the child while practicing talking techniques, turn-taking, and so forth. At this time the parents are coached and encouraged by teachers. Bilingual teachers, aides, and interpreters are present to facilitate smooth and accurate communication.

During the second and third hours the children stay in the nursery school with the teachers while the parents attend their classes. First the Spanish-speaking parents meet with the bilingual counselor for

theme-oriented discussion. The topics range from grieving and family relationships to behavior management and routines. Parents are given some information and printed handouts and then they share their own experience around each topic.

The third hour is spent in an English as a Second Language class which assists the parents in making the transition to English in the home. The language taught is oriented to that which is used with babies and preschoolers in play, household routines, clinic routines, and the day to day life of a family. Parents are encouraged to use the simple phrases and sentences they've learned in class all week at home. They bring in questions about how to say specific things to their children. The transition to English in the home, as well as at the Clinic, is made gradually with much support, encouragement and coaching.

Most children are first brought for services between birth and two and one half years old, often without hearing aids yet. They have not yet established a Spanish language base, so there is not as much confusion for them in being exposed to English as there would be for an older hearing-impaired child. Therefore the negative impact of exposure to English is minimized. Often children will have older siblings who speak to them in English, which they use among themselves, having learned it at school.

New arrivals to John Tracy Clinic are invited to parent classes. If they decide that they like and want to commit to our program then they are given a demonstration home appointment. The parent (or parents) brings the hearing-impaired child and any other children that are not in school to a weekly appointment with the demonstration home teacher. Classes take place in what looks like a roomy

bachelor apartment which is full of the toys, appliances, and furniture that are found in most homes. The principle objectives of these classes are to train the parent to use daily home routines to teach, practice, and enhance oral communication skills and encourage language acquisition in her young child. The teacher gives the lesson, which is active and participative, in English while an interpreter translates all information and questions that are exchanged. The Spanish counselor is available after the demonstration home appointment to discuss any behavior, relationship, or affective concerns.

Nursery school takes place four days a week. The criteria to enter nursery school include parental interest, demonstration of consistent parental commitment to the Clinic's program through regular attendance, the understanding and practicing of skills taught in parent classes and demonstration home, the regular practice and improvement in English by the parents, and the child's developmental readiness and degree of deafness. (We only accept children in the severe to profound ranges). Many families choose to send their children to public schools after attending demonstration home.

Children may enter nursery school as early as twenty-four months and graduate at age five, at which time they enter public schools.

There is a bilingual tutor and a bilingual aide in the nursery school who provide interpretation when necessary. But the parent is expected to use English in the classroom. Parents stay in the classroom one day a week to learn and practice teaching advanced language and speech techniques to hearing-impaired children. They are also expected to plan

and teach lessons to the children on a regular basis. The parents spend a lot of time in the observation booths watching classroom activities through one way mirrors and absorbing information and more English language. Many Hispanic parents attend English as a Second Language classes at a nearby adult school on the three days that they don't participate in the classrooms. This enriches their English vocabulary so that they can stay ahead of their chldren enough to continue to teach them.

The John Tracy Clinic correspondence course is offered in Spanish worldwide. This is also made available to the Hispanic families who use our services as a supplement to the information and practice they are already getting.

By the time families graduate from nursery school, both the parents and most of the hearing-impaired youngsters have developed fluency in English. More importantly, the parents are equipped with the tools they need to continue to take responsilibity for their childrens' education. They feel empowered by their now well-developed skills and knowledge and are prepared to face the English-speaking world of educational and medical institutions with the skills and confidence needed to be their child's primary advocate.

For more information write to:

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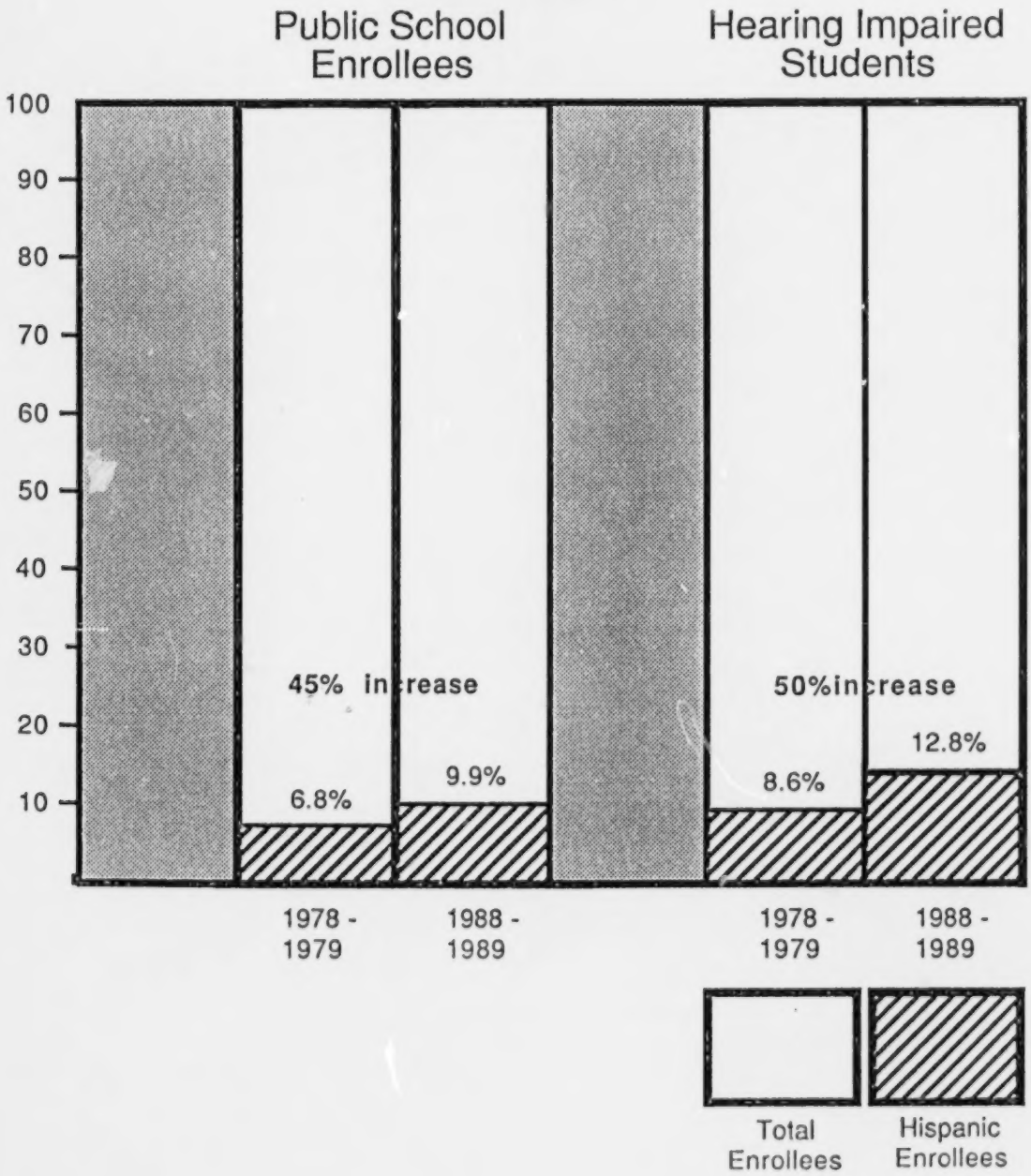
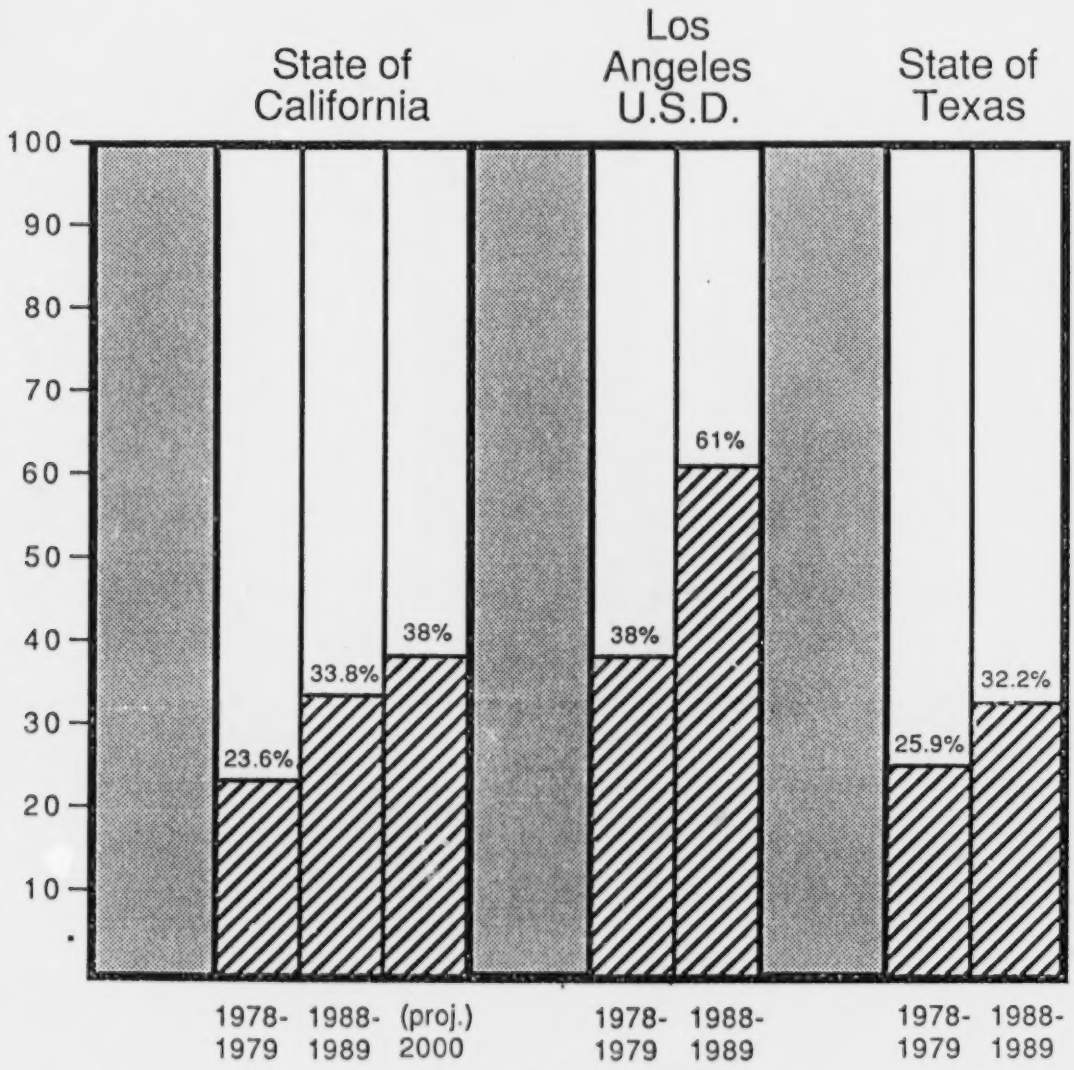
Percentage of Hispanics Enrolled in U.S. School Programs



Graph No. 20

Percentage of School Age Hispanics (Ages 5 - 19)



Graph No. 2

PROGRAM FOR HISPANICS AT JOHN TRACY CLINIC

COMPONENT	HOW HISPANICS' NEEDS ARE ACCOMMODATED
1) Audiological Services	Interpreters present to facilitate communication with the audiologist.
2) Parent Classes	Bilingual professionals teach beginning classes in Spanish. Classes in English are simultaneously interpreted.
3) Parent Support Group	Bilingual counselor facilitates group, which takes place in Spanish.
4) Weekly parent-child playtime (Practice of talking techniques)	Bilingual educators, teacher aides, and interpreters are present to coach and encourage talking techniques.
5) E.S.L. Classes	Offered to Spanish-speaking parents to facilitate their transition to English.
6) Demonstration Home	Interpreters are present to facilitate communication between individual family and teacher.
7) Counseling	Bilingual counselor is available to serve families as needed.
8) Nursery School	English skills are expected. Interpretation as needed by bilingual educators or aides.
9) Correspondence Course	Offered in Spanish both worldwide and as a voluntary supplement to families enrolled in other Clinic services.